



FAILED BY THE SYSTEM

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Why the Employment and
Support Allowance isn't working
for people living with cancer

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Executive summary

Employment and Support Allowance (ESA) was introduced in October 2008, replacing incapacity and income support for people off work long-term due to ill health or disability. The benefit was designed to actively encourage the more 'job ready' claimants to move off benefits and return to work. At the time, the government made assurances that the very sick or disabled – including chemotherapy patients and terminally ill people – would be protected and hence would not be required to attend medical assessments or work-focused interviews. Certain safeguards were included to protect these people. However, these safeguards are not working. Poor knowledge of the ESA rules within Jobcentres, poor systems and poor understanding of cancer and its effects, mean many vulnerable people with cancer are getting a poor deal.

Macmillan Cancer Support and Citizens Advice have worked together to collate evidence demonstrating the key problems people with cancer are experiencing accessing ESA. Since May 2009, the Macmillan Benefits Helpline has received 661 calls about ESA and Citizens Advice bureaux have dealt with more than 85,000 enquiries about ESA since April 2008, gradually building up to the launch of the new benefit in October 2008. Between January and October 2009, Citizens Advice bureaux received 61,254 enquiries about the benefit.

Our advisers have identified three key ways in which the new ESA system is failing people with cancer:

- Terminally ill patients are not being fast tracked into the ESA support group and are being required to undergo the work capability assessment or attend work-focused interviews.

- Cancer patients receiving chemotherapy are being asked to attend a work capability assessment or work-focused interviews.
- The work capability assessment, which is used to determine if someone is eligible for ESA and should be taking part in work-related activity, is not sensitive to the problems faced by people with cancer.

This report looks at these issues in more detail. Citizens Advice is also publishing a series of working papers on ESA, the first of which covers the administration of the claiming process for ESA, including claiming by telephone, poor advice, and delays in the process. Subsequent papers will focus on the work capability assessment, decision-making and appeals, and the use of sanctions in ESA.

Introduction

Approximately 300,000 people are diagnosed with cancer in the UK and 150,000 die from the disease each year¹. However, due to improvements in treatments and diagnosis, more and more people are surviving the disease – there are now two million people in the UK living with or beyond cancer². Some return to good health and employment after cancer but may be unable to work while undergoing treatment such as chemotherapy, radiotherapy or surgery. The side effects of these treatments can be particularly debilitating and include nausea, severe fatigue and an impaired immune system. In addition, the patient is required to attend regular medical appointments for treatment or check ups over a set period of time, often interfering with working life.

Other people with cancer may be left to cope with the long term effects of cancer and its treatment which can include urinary or bowel problems, osteoporosis and depression. Their ongoing disabilities may limit their capacity for work. Those with a terminal diagnosis who are often extremely unwell are incapable of working.

Approximately 90,000 people of working age are diagnosed with cancer each year in the UK³

and there are 774,000 people of working age in the UK who have had a cancer diagnosis⁴. International evidence suggests around 60% of people diagnosed with cancer return to work. For many people with cancer who are unable to work due to sickness or disability, the financial impact of cancer means that any funds can be quickly depleted and they rely on the state for financial support – their main source of income often being ESA.

1 Cancer Incidence and Mortality rates, Cancer Research UK <http://info.cancerresearchuk.org/cancerstats/incidence/index.htm>, <http://info.cancerresearchuk.org/cancerstats/mortality/index.htm>

2 King's College London, Macmillan Cancer Support, National Cancer Intelligence Network Cancer Prevalence in the UK 2008.

3 Department of Health, Cancer Reform Strategy, December 2007, p80

4 King's College London, Macmillan Cancer Support, National Cancer Intelligence Network Cancer Prevalence in the UK 2008.



'I really don't know how a random doctor can decide whether someone's fit to work in 30mins. I went through a farcical medical interview only to be told that I didn't have enough points to continue getting ESA. I take anti-depressants and anti-psychotic drugs to deal with the psychological impact of cancer. I may be physically fit to work, but I'm not mentally ready. Both my GP and psychiatrist agreed that I was too ill to work. Thankfully, with the help of my mental healthcare nurse, I managed to get the decision overturned, but I'm sure an awful lot of people feel unable to challenge the system.'

Amanda Whetstone from Surrey

Employment and Support Allowance

ESA was introduced in October 2008 to replace Income Support and Incapacity Allowance for those people who are not in work due to reasons of disability or sickness. Under the new system people are encouraged to return to work. After an initial assessment period of 13 weeks, claimants undergo the work capability assessment. This consists of a self-assessment questionnaire completed by the claimant, followed by a medical examination with a doctor from the DWP medical service to determine if the person has limited capacity for work and is therefore entitled to ESA.

Certain groups of people automatically qualify for ESA (are found to have limited capacity for work) without having to satisfy the work capability assessment. This includes:

- the terminally ill⁵,
- anyone receiving non-oral (intravenous, intraperitoneal or intrathecal) chemotherapy⁶ or recovering from that treatment,
- an inpatient in hospital or recovering from treatment as an inpatient,
- anyone receiving radiotherapy or recovering from that treatment⁷
- and those who put at risk their or anyone else's mental or physical health by working⁸.

Those who qualify for ESA are then assigned into one of two groups after an assessment of whether they are too ill or severely disabled to be expected to undertake work-related activity (ie, they have limited capacity for work-related activity). The test has a list of 46 descriptors, relating to both physical and mental functions.

If at least one of them fits, the person is placed in the support group of claimants. In the work-related activity group claimants are required to attend work-focused interviews and take part in the government's Pathways to Work programme. Those claimants who have been found to have limited capacity for work-related activity are assigned into the support group. In this group claimants are not required to attend work-focused interviews or undertake work-related activity.

Anyone who is terminally ill (and who could be 'reasonably expected' to die within the next six months) should be automatically fast tracked into the support group without having to wait out an assessment period of 13 weeks. In addition other criteria mean that those claiming ESA automatically qualify for the support group without having to undergo a work capability assessment; eg anyone receiving intravenous, intraperitoneal or intrathecal chemotherapy or recovering from that treatment.

5 This means the claimant is suffering from a progressive disease and death in consequence of that disease can reasonably be expected within six months

6 This does not include those receiving oral chemotherapy.

7 The claimant must be undergoing at least two days of treatment per week, recovering from that treatment for at least two days of treatment per week or undergoing one day of treatment and one day of recovery per week. The two days need not be consecutive.

8 This would include those whose immune system has been impaired through treatment.

Failing people with cancer

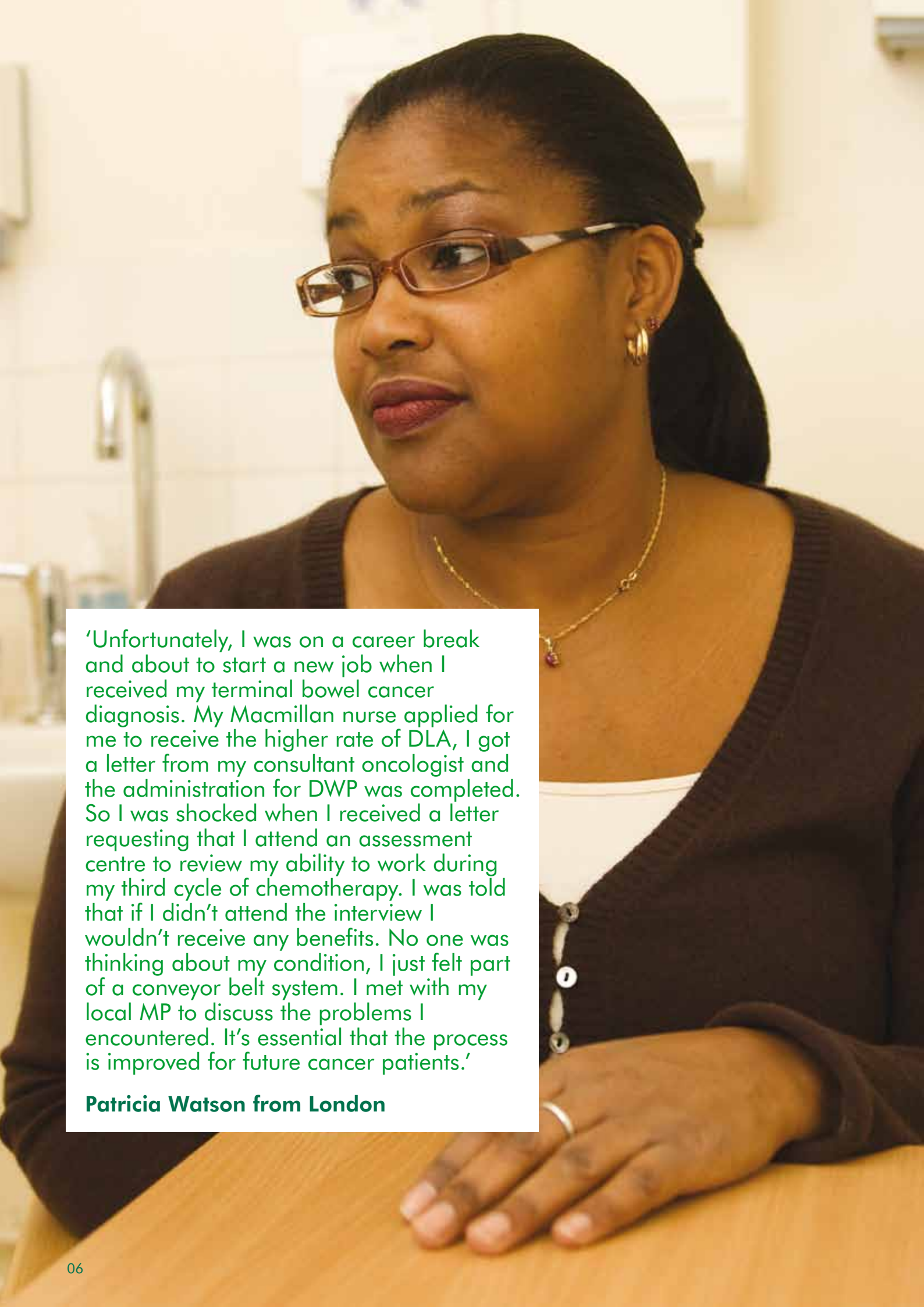
Macmillan Cancer Support has a network of benefit advisers across the UK as well as a national benefits advice line helping thousands of people with cancer to navigate the benefits system and cope with financial difficulties. Macmillan Cancer Support works closely with the Citizens Advice service and other advice specialists, and together we have established benefits advice services in cancer centres across the UK.

Macmillan Cancer Support and Citizens Advice Bureau advisers have identified three key ways in which the new ESA system is failing people with cancer:

- Terminally ill patients are not being fast tracked into the support group.
- Cancer patients receiving chemotherapy are not automatically being assigned into the support group and groups such as radiotherapy patients are not automatically qualifying as eligible for ESA.
- The work capability assessment is not sensitive to the problems faced by people with cancer.

There appears to be a lack of knowledge of the ESA rules among Jobcentre Plus and the DWP medical service staff, resulting in people being assigned to an inappropriate group or incorrectly being paid the lower rate of ESA. In addition a general lack of understanding of the impacts of cancer, cancer treatment and associated side effects mean that staff members are not interpreting the rules correctly, or not fully appreciating the effects of someone's illness or disability. Finally there appears to be a mismatch between the ESA rules and what the systems used by Jobcentre Plus and DWP actually allow, which causes delays and confusion.





'Unfortunately, I was on a career break and about to start a new job when I received my terminal bowel cancer diagnosis. My Macmillan nurse applied for me to receive the higher rate of DLA, I got a letter from my consultant oncologist and the administration for DWP was completed. So I was shocked when I received a letter requesting that I attend an assessment centre to review my ability to work during my third cycle of chemotherapy. I was told that if I didn't attend the interview I wouldn't receive any benefits. No one was thinking about my condition, I just felt part of a conveyor belt system. I met with my local MP to discuss the problems I encountered. It's essential that the process is improved for future cancer patients.'

Patricia Watson from London

Terminally ill patients

Under the ESA rules people who are terminally ill should be fast tracked into the support group without having to wait out the assessment period or undergo a work capability assessment. However, in practice both Macmillan and Citizens Advice Bureau advisers tell us that many terminally ill people are being called for work capability assessments or failing to be automatically assigned, meaning they are missing out on a higher and much needed rate of benefit. In some cases such delays mean the claimant dies before receiving the financial help they needed.

The easiest way for a person to 'prove' that they have a terminal diagnosis is to obtain a DS1500 form from their doctor – usually as part of a claim for disability living allowance (DLA). However, Jobcentre Plus staff have shown a lack of knowledge with regard to the fast tracking of terminally ill patients and seem unfamiliar with terms such as DS1500 or the rules for DLA. In some instances they may be disregarding the system already in place for DLA and requiring the process be started afresh for ESA.

A self-employed woman in her 50s with terminal and inoperable pancreatic cancer contacted the Macmillan helpline. She was advised to claim ESA and inform the Jobcentre Plus that she was terminally ill and was going to claim DLA supported by a DS1500 form. Six weeks later she was sent a self-assessment questionnaire and told to attend a work-focused interview. The woman had to send the Jobcentre Plus a copy of her DS1500 form twice before she was assigned correctly to the support group. Even then the woman was still receiving ESA at a lower, incorrect level.

A terminally ill man in his 50s from the East Midlands was called for a work capability assessment five months after first claiming

ESA despite qualifying automatically for the support group. During this five month period he was receiving ESA on the lower and incorrect rate. At the medical assessment, the doctor did not interview or examine the man as it was very clear he was not capable of work.

The following case demonstrates that there is a mismatch between the ESA legislation intent and the administrative reality:

A man in his 50s from South West England was suffering from terminal prostate cancer and secondary bone cancer, as well as depression. He had applied for DLA using a DS1500 form. When claiming for ESA he did not include his DS1500 form as the ESA form said this was not necessary if one had already been included in a claim for DLA. However, the ESA claim was processed before the DLA application which meant he was not assigned to the support group and received ESA at the lower rate. DLA was awarded but there was no automatic procedure which allowed this information to be passed between the DLA and ESA sections of DWP, leaving the man to continue having to chase to be placed in the correct group for ESA.

Chemotherapy and radiotherapy patients

Under the ESA rules anyone receiving non-oral (intravenous, intraperitoneal or intrathecal) chemotherapy or recovering from that treatment, should automatically qualify for the ESA support group without having to undergo the work capability assessment. Other groups automatically qualify as having limited capacity for work – and are therefore entitled to ESA – without having to satisfy this part of the work capability assessment.

This includes

- an inpatient in hospital or anyone recovering from treatment as an inpatient
- anyone receiving radiotherapy or recovering from that treatment
- those who put at risk their or anyone else's mental or physical health by working.

Again, case studies from both Macmillan and Citizens Advice Bureaux show that in practice there is lack of understanding among Jobcentre Plus and the DWP medical services staff of many cancer treatments and the rules around automatic qualification for ESA or for the support group. Claimants are asked when they make the claim if they are undergoing any special treatment such as chemotherapy but are not asked to describe the treatment. If staff members are unfamiliar with technical or medical terminology then insufficient information is captured to properly process the claim. Therefore, patients undergoing non-oral chemotherapy are being asked unnecessarily to attend the work capability assessment, while radiotherapy and inpatients are being denied ESA.

A woman contacted the Macmillan helpline about her ESA claim. After undergoing surgery for cancer, she had a Hickman line put in

place to receive chemotherapy intravenously. A Hickman line is a hollow tube which is inserted into one of the large blood vessels through a small cut in the upper chest, passed along the large blood vessel until it reaches the entrance to the heart and then comes out through a small cut in the lower chest. This allows permanent access for administration of chemotherapy. She had received requests to attend a work capability assessment and was told by Jobcentre Plus staff that nobody is exempt from these. However, since she was receiving non-oral chemotherapy this information was incorrect.

Another man, receiving intravenous chemotherapy via a peripherally inserted central catheter (PICC) line, contacted the Macmillan helpline about his ESA claim. A PICC line is a hollow tube which is inserted through veins in the arm and passed along the large blood vessel until it reaches the entrance to the heart. A PICC line allows permanent access for administration of chemotherapy. Although he disclosed this information when claiming for ESA he was not automatically assigned to the support group. The Jobcentre Plus staff did not know what a PICC line was, nor how this would affect his ESA claim.

In addition if staff are unclear about the effects of cancer treatment they may not understand the length of time it can take a patient to recover from surgery, chemotherapy or radiotherapy.

A woman with breast cancer from South West England was in receipt of ESA. However, while recovering from chemotherapy treatment she was upset to receive a limited capability questionnaire.

There are also problems if the patient is not clear what treatment they will be undergoing at the time

of application for ESA, resulting in delays to their claim, or incorrect assignment to the work-related activity group.

A woman from South West England required intensive radiotherapy after surgery for cancer. However at the time of claiming ESA, the hospital had not yet confirmed the dates. The woman was therefore required to attend a work capability assessment but when she got there the assessors were 'horrified' that she had been made to attend.



Work capability assessment

The work capability assessment primarily determines whether the claimant is entitled to ESA. In addition, if claimants were not assigned into the support or work-focused activity group earlier in the application process, then the work capability assessment will determine this. The limited capacity for work assessment considers physical and mental functions and a claimant must score 15 points to be deemed to have limited capacity for work. The limited capacity for work-related activity assessment has a list of 46 descriptors, relating to both physical and mental functions. If at least one of them fits, the person is placed in the support group of claimants.

People with cancer have complained that the assessment is not thorough enough, does not allow them to properly explain the problems they face and that the doctors are not always familiar with these difficulties or problems. This means they are inadvertently being denied ESA or assigned into the group requiring them to attend work-focused interviews and undertake work-related activity. In addition this can affect the amount of benefit the person receives because they may be placed on the lower rate when in fact they are entitled to the higher rate.

A man from East Anglia had been self-employed but could no longer work due to cirrhosis of the liver, hepatitis C and suspected cancer of the oesophagus. His ESA claim was refused following a capability for work assessment. The man scored six points under walking and six under standing/sitting. The man believed other problems were not properly considered such as swelling of the legs later in the day, which prevents him from bending, and bowel problems.

Another woman in remission from breast cancer from North England had previously been in receipt of incapacity benefit. After undertaking the work capability assessment

she was found not to qualify for ESA having scored only one point. The test lasted only 25 minutes and appeared to have recorded that she could carry out tasks that she could not. The woman intends to appeal this decision.

The following case shows that the work capability assessment is not necessarily flexible enough to truly take account of someone's situation and that the ESA process does not make provision for those individuals whose treatment has yet to be confirmed. The claimant was found fit to work using the point scoring system, but as she was due to undergo intensive treatment this would clearly not be possible in the near future.

A woman in her 50s from South East England had cancer of the face and applied for ESA. She was called for a work capability assessment before her treatment began. In the assessment she scored six points and was found fit to work, although the medical examiner's report stated that a return to work could only be considered after six months. Two weeks later she began oxygen therapy for five hours a day, four days a week. After this she was due to undergo surgery before further post-operative oxygen therapy.

Recommendations

While ESA is only just a year old and teething problems are therefore expected, Macmillan and Citizens Advice believe more could be done to protect vulnerable people with cancer. The DWP must take urgent action to explore why these problems are occurring and to address them. We recommend:

The DWP must improve communication between the Pension, Disability and Carers Service and Jobcentre Plus so that claims under 'special rules' criteria are fast tracked and handled efficiently, so avoiding unnecessary distress to terminally ill people and their families.

Jobcentre Plus must ensure that both contact staff and advisers are fully trained and aware of the ESA rules for those who are terminally ill, receiving chemotherapy, undergoing radiotherapy or an inpatient. Staff must be trained to recognise terms such as 'Special Rules' and 'DS1500' and their implications regarding terminal illness and ESA.

An independent review of the work capability assessment is needed to determine if it is effectively capturing the problems and disabilities faced by people with cancer.

The DWP must ensure that Jobcentre Plus staff and ATOS medical assessors are equipped to ask claimants the right questions in order to gather accurate and substantial evidence about their cancer treatment so that they are correctly assessed for ESA.

The DWP should change the rules for people who have been diagnosed with cancer but have not started treatment. We would suggest that those diagnosed with cancer and awaiting confirmation of their treatment be assigned into the support group until their treatment regime and timings have been confirmed.



About us

About Macmillan Cancer Support

Macmillan Cancer Support is a UK charity working to improve the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care. We have developed a network of cancer specific, local benefits advice provision to support people affected by cancer.

The Citizens Advice service

The Citizens Advice Bureau service is a network of 416 independent Citizens Advice Bureaux that provide free, independent and impartial advice from more than 3,000 locations in England and Wales.



If you have any questions about cancer, ask Macmillan.
If you need support, ask Macmillan.
Or if you just want someone to talk to, ask Macmillan.

Our cancer support specialists are here for everyone
affected by cancer, whatever you need.

Call free on **0808 808 00 00**,
Monday to Friday, 9am to 8pm

www.macmillan.org.uk

We have an interpretation service in over 200 languages.
Just state, in English, the language you wish to use when you call.

If you are deaf or hard of hearing, you can use our textphone service
on **0808 808 0121**, or the Text Relay system.

Contact **Jennifer Mitchell**,
email **jmitchell@macmillan.org.uk**
or go to **www.macmillan.org.uk**



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